

SURVEY OF PARENTS WHOSE CHILDREN SUFFER FROM LARYNGOMALACIA

Summary of Survey Methodology

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Introduction

The Oregon Survey Research Laboratory (OSRL) was asked to conduct research on the parents and caregivers of children who have suffered from Laryngomalacia. Working closely with Dr. Henry Milczuk from the Oregon Health Sciences University, OSRL planned, pretested and implemented a telephone survey of 44 caregivers. This report summarizes the survey methodology.

Survey Methodology

Survey Instrument

In designing the survey instrument previous work on quality of life was examined. Some of the questions used are similar to those in other quality of life surveys. Most of the questions are OSRL originals created in consultation with Dr. Milczuk.

The survey instrument was programmed into OSRL's computer-aided telephone interviewing (CATI) system and pre-tested on medical experts and caregivers familiar with Laryngomalacia. All interviews were completely confidential, and human subjects approval was obtained at both the Oregon Health Sciences University and the University of Oregon.

Sample and Data Collection

Subjects for this survey were selected from Dr. Milczuk's patient records. Dr. Milczuk contacted all available parents, or caregivers, of patients diagnosed with Laryngomalacia in during the years 1993 - 1997. Subjects were asked if they would be willing to participate in a study about the effects on parents and caregivers of having a child with Laryngomalacia. All parents and caregivers that could be contacted agreed to participate in the survey. All potential participants were read a consent letter informing of the risks of participating and explaining their right to refuse any question or quit the study at any time. If, when conducting the survey, respondents did not recall the consent letter it was read to them again before any questions were asked.

Dr. Milczuk gave the respondent sample list to OSRL. The Oregon Survey Research Laboratory conducted interviewer training on January 6, 1999. Interviewing began on January 9, 1999 and finished on March 8, 1999. Interviewing was conducted intermittently from 9:00 AM until 9:00 PM, Monday through Sunday, until the target sample size of more than 40 was achieved. Altogether, OSRL interviewers completed 44 interviews, representing the parents and caregivers of 32 children who have suffered from Laryngomalacia. Up to 25 calls were made to each valid telephone number. Interviews were conducted in English and Spanish.

Survey sampling errors are calculated to assist data users in assessing how much confidence to place in a particular survey result. The Oregon Survey Research Laboratory interviewed 82% of the eligible parents and caregivers in the sample, and no subject who was contacted refused an interview (see Sample Report). From the eligible population of 65 parents and caregivers, OSRL's 44 respondent interviews represents an accuracy of $\pm 8.4\%$ on any question with a roughly 50/50 proportional split, and an accuracy of $\pm 6.7\%$ for an 80/20 proportional split. This means that when an answer is generalized back to the entire subject population that the appropriate error bar needs to be placed around any given result.

When subgroups of respondents are examined the accuracy of any specific result declines. Because of the relatively small sample size of this study, subgroups often contain only a few subjects and consequently the accuracy of their answers is less certain than the accuracy of any answer that uses the entire subject population.

It is important to remember that the subject population is not drawn randomly from the universe of parents and caregivers whose children suffer from laryngomalacia, but from a single physician's (Dr. Milczuk) patient records. Consequently, the results of this study, while suggestive, are not generalizable to the broader universe of laryngomalacia caregivers.